# BRAIN INJURY IN KENTUCKY

STATUS REPORT
January 2004

Submitted by

The Kentucky Traumatic Brain Injury Trust Fund
Board of Directors

Board of Directors
Traumatic Brain Injury Trust Fund
C/o Brain Injury Services Unit
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# Introduction

There is increasing awareness of the serious public health problem posed by the growing number of people with acquired brain injuries throughout Kentucky. With advances in accident rescue, hospital trauma services, and other medical and early psychosocial interventions, more people survive brain injuries than ever before. However, these medical advances have resulted in an ever increasing number of persons with life-long and potentially severe disabilities.

It is conservatively estimated that more than 5,000 individuals sustain brain injuries across the state each year (Christian, 2001, 2002, 2003) and an estimated 19.4% of all Kentucky households have one or more members who have sustained a head injury (Walker, Logan, Leukefeld, & Stevenson, 2004). The number of persons in Kentucky with brain injuries severe enough to require services and supports is currently estimated to be between 202,488 and 214,032 (Walker, et al., 2004). Due to the annual incidence of brain injury within the state, the number of people in need of such help can only be expected to grow.

An acquired brain injury often results in permanent changes to a person's ability to maintain employment, interpersonal relationships, and independent living. Psychological and behavior problems, personality changes, sleep disturbances, impaired concentration and memory, or health problems commonly result from a brain injury. Even a "mild" brain can have devastating financial, emotional, and social consequences for an individual and for the family.

The growing number of citizens with disabilities resulting from acquired brain injuries makes careful planning for the development of services and supports to meet their needs imperative. This status report, prepared by the Kentucky Traumatic Brain Injury Trust Fund Board, presents current information about brain injury in the state, the service needs that Kentuckians experience as they cope with the effects of brain injuries, the state of the service delivery system available to them, and a comparison of funding provided for other disability groups. Recommendations for the further development of services and supports to this underserved population are presented.

## About the Traumatic Brain Injury Trust Fund
## Board of Directors

The Board of Directors of the Traumatic Brain Injury Trust Fund was established in 1998 by KRS 211.472. It is attached to the Cabinet for Health Services for administrative purposes. The Board is composed of nine members: six who are appointed by the Governor and three who are established in the legislation and designated by their positions within state government. The Board has governing authority, and per the establishing legislation, KRS 211.474, is responsible to:

- Promulgate administrative regulations related to the administration of the Trust Fund
- Formulate policies and procedures for determining individual eligibility for assistance from the trust Fund
- Establish a registry for traumatic brain and spinal cord injuries
- Investigate the needs of brain-injured individuals and identify gaps in current services
- Assist the Cabinet for Health Services in developing programs for brain-injured individuals
- Monitor and evaluate services provided by the Trust Fund
- Provide the Governor, the General Assembly, and the Legislative Research Commission an annual report by January 1st of each year

The Board is submitting this status report in keeping with its legislative mandates to identify the needs of people with brain injuries, identify gaps in services, and assist in the development of programs for this population.

Board members for 2003 included:

Mary Hass, Chair, designee for Scott Furkin, Executive Director of the Brain Injury Association of Kentucky
Margaret Pennington, Commissioner, Department for Mental Health and Mental Retardation Services, designee for Marcia Morgan, Secretary, Cabinet for Health Services
Dr. Steven Englender, State Epidemiologist
Dr. George Raque, Neurosurgeon
Dr. Margaret Dubicki, Neuropsychologist
Dr. Dan Gripshover, Rehabilitation Specialist, Neuropsychologist
Robert Walker, LCSW, Social Worker
Elizabeth Runyon, RN, MSN, Family Member
Kathy Williams, M.A., Family Member

Staff support to the Board is provided by the Brain Injury Services Unit within the Department of Mental Health and Mental Retardation Services.

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Note: Reference is made throughout this report to traumatic brain injuries and acquired brain injuries. A traumatic brain injury is commonly understood to be an injury to the brain resulting from a blow to the head. The term acquired brain injury refers to an injury that may result from a variety of factors, including, a lack of oxygen, exposure to toxic substances, allergic reactions, infection, or similar events. Kentucky has chosen to serve persons with acquired brain injuries, rather restricting services to the narrower category of traumatic brain injuries.

## I. Incidence and Prevalence of Brain Injury in Kentucky

Pursuant to its legislative mandates to investigate the needs of persons with brain injury, identify gaps in current services and assist the Cabinet for Health Services in developing programs for brain-injured individuals, the Traumatic Brain Injury Trust Fund Board of Directors (the Board) funded two large scale data collection projects. Beginning in 2000, the Board has funded the Brain Injury and Spinal Cord Injury Surveillance project, which is completed annually by the Kentucky Injury Prevention and Research Center at the University of Kentucky. Data from this project provides an estimate of the number of people treated for brain injuries in hospitals and trauma centers, as well as those who die as a result of brain injuries in a given year. This establishes the estimated annual incidence, or number of occurrences, of brain injury in the state.

In November 2002, the Board commissioned a Household Prevalence Study to provide an estimate the total number of individuals in Kentucky who have been affected by head injuries. This telephone survey of 3,267 randomly selected households was conducted by the University of Kentucky Center on Drug and Alcohol Research and the Survey Research Center. Participants were asked questions about the occurrence of a head injury within their households and any changes to the health or behavior of the affected individual subsequent to such an injury. Additional questions were asked about service needs and utilization, and demographic data.

Information about the incidence and prevalence of brain injury in Kentucky has been derived from these two sources for this paper and has been used to answer the questions highlighted below.

### How many people sustain brain injuries each year in Kentucky?

Table 1. Estimated Incidence Rates of Traumatic and Acquired Brain Injury in Kentucky in 2000 (Christian, 2001, 2002, 2003)

| Year | TBI incidence estimate | Estimated number | ABI incidence estimate | Estimated number |
|---|---|---|---|---|
| 1998 | 62.5 / 100,000 | 2,304 | 40.0 / 100,000 | 1,475 |
| 1999 | 76.7 / 100,000 | 2,828 | 55.9 / 100,000 | 2,061 |
| * 2000 | 96 / 100,000 | 3,880 | 78.6 / 100,000 | 3,176 |

** increases may be due to improved data reporting*

Figures 1 and 2 illustrate the number of persons by county who sustained traumatic and acquired brain injuries, respectively, in 2000.

**Figure 1. Number of People with New Traumatic Brain Injury by County in 2000**

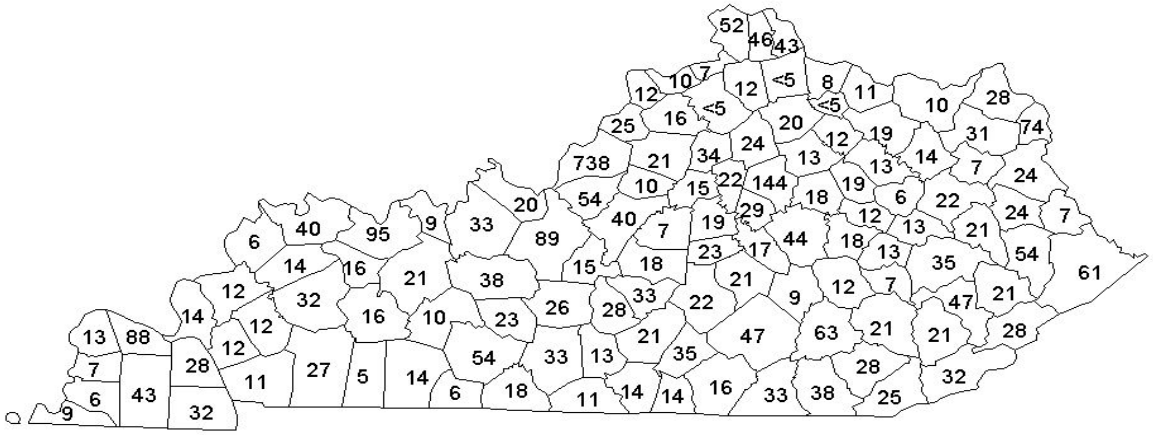
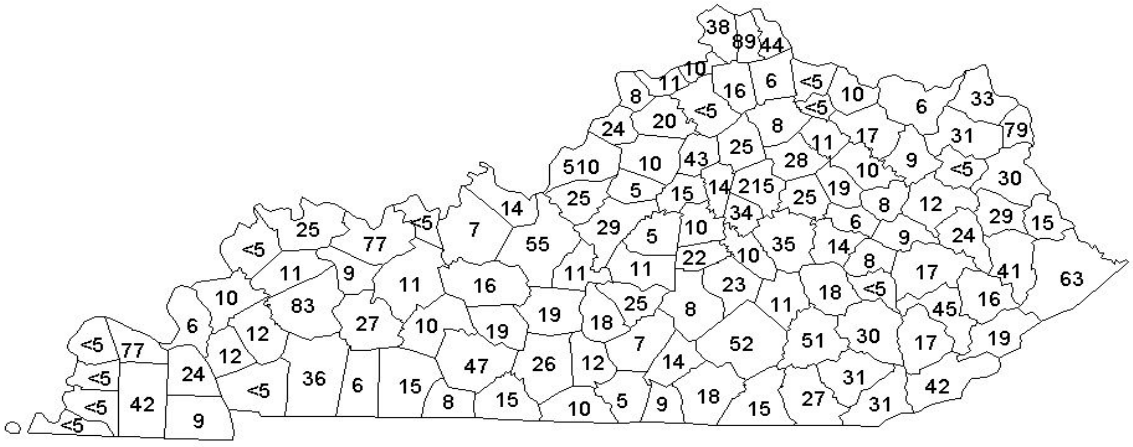



**Figure 2. Number of Persons with New Acquired Brain Injury by County in 2000**




Source: Christian, 2001, 2002, 2003

## What is the prevalence of brain injury in Kentucky?

Table 2 shows the regional distribution of households, using designated Mental Health Regions, among 3,267 randomly selected households surveyed, reporting at least one member with a brain injury, as reported by Walker, et al., 2004. A total of 633 households reported at least one person with a brain injury. By extrapolation, it can be estimated that 19.4% - or 308,586 - of all Kentucky households have been affected by brain injury. The percentage of individual people identified within the sample who reported a brain injury was 12.2%. Again, by extrapolation, it can be **estimated that 493,096 people in Kentucky have sustained a brain injury**. However, not all of these injuries have resulted in lasting impairments or disabilities.

Table 2 also presents the 2000 census population for each region. The distribution of households, among those randomly selected for the prevalence survey, with persons reporting brain injuries is consistent with regional population distribution, suggesting that there are no significant regional differences in prevalence.

**Table 2. Distribution of Households Reporting One or More Members with Brain Injury by Mental Health Regions (n=633)**

| Mental Health Region | Households with Injured Persons | Percent of total sample | 2000 Census Regional Population | Percent of Total State Population |
|---|---|---|---|---|
| 1 Four Rivers – Paducah | 29 | 4.6 | 203,299 | **5.0** |
| 2 Pennyroyal – Hopkinsville | 21 | 3.3 | 205,715 | **5.1** |
| 3 Valley – Owensboro | 39 | 6.2 | 207,377 | **5.1** |
| 4 Lifeskills – Bowling Green | 23 | 3.6 | 255,225 | **6.3** |
| 5 Communicare - Elizabethtown | 51 | 8.1 | 243,202 | **6.0** |
| 6 Seven Counties – Louisville | 132 | 20.9 | 869,306 | **21.5** |
| 7 NorthKeY – Covington | 53 | 8.4 | 391,417 | **9.7** |
| 8 Comprehend- Maysville | 9 | 1.4 | 55,229 | **1.4** |
| 10 Pathways – Ashland | 33 | 5.2 | 212,086 | **5.2** |
| 11 Mountain – Prestonsburg | 19 | 3.0 | 160,532 | **4.0** |
| 12 Kentucky River – Jackson | 25 | 3.9 | 120,656 | **3.0** |
| 13 Cumberland Valley – Corbin | 49 | 7.7 | 238,270 | **5.9** |
| 14 Adanta – Somerset | 37 | 5.8 | 193,452 | **4.9** |
| 15 Bluegrass – Lexington | 113 | 17.9 | 686,003 | **17.0** |
| Total | 633 | 100.0 | 4,041,769 | **100.1**[a] |

*Sum over 100% due to rounding*

## How old are people at the time of injury?

Table 3 shows the age of the person at the time of the reported injury, for those respondents of the prevalence survey conducted by Walker, et al., 2004. Over half (60%) of the injuries occurred among persons under 21 years of age. The prevalence of reported injuries among Kentucky households decreased among older persons with the over 50 year-old group reported as only 6.9% of the total head injured persons.

**Table 3. Age at the Time of the Head Injury (n=403)**

| Injured persons still living in the household | Number of Injured Persons | Percent |
|---|---|---|
| Under age 21 | 462 | 60 |
| Between the ages of 21-30 | 130 | 16.9 |
| Between the ages of 31-40 | 77 | 10 |
| Between the ages of 41-50 | 48 | 6.2 |
| Over the age of 50 | 53 | 6.9 |

## What are the major causes of brain injury?

Tables 4 and 5 detail the major causes of traumatic and acquired brain injury, respectively, using the most recently available data, from the year 2000, as reported by Christian, 2003. The most frequent cause of a brain injury in Kentucky is a motor vehicle accident, including all terrain vehicles and motorcycles. It is important to note that a study of the predictors of brain injuries among motorcycle riders has shown that lack of helmet usage is one of the most powerful factors, even more powerful than alcohol intoxication, in predicting who sustains a traumatic brain injury in motorcycle crashes (Christian, Carroll, Meyer, Vitaz, & Franklin, 2003).

**Table 4. Major causes of Traumatic Brain Injury in 2000**

| Cause | % of total |
|---|---|
| Motor vehicle crash | 38.0 |
| Other transport injury | 11.3 |
| Suicide / Self-inflicted | 7.3 |
| Other unintentional injury | 6.7 |
| Homicide / Assault | 5.9 |
| Fall | 20.0 |
| Unknown | 10.8 |
| Total | 100 |

**Table 5. Major causes of Acquired (Non-Traumatic) Brain Injury in 2000**

| Cause | % of total |
|---|---|
| Injury (includes poisoning) | 40.0 |
| Anoxia | 23.8 |
| Multiple causes | 11.5 |
| Infectious disease | 1.4 |
| Other | 23.3 |
| Total | 100.0 |

**Conclusion:**

The incidence of brain injury in Kentucky is significant, with an estimated 5,000 or more children and adults being injured annually. Prevalence estimates show that as many as 493,096 persons within the state have sustained a brain injury ranging from mild to severe. Given the continuing occurrence of brain injury, the number can only be expected to increase with time.

Prevalence estimates also show that brain injury is problematic throughout the state and is not limited to major population centers. This suggests a need to develop an infrastructure to provide needed supports and services in the rural as well as in the metropolitan regions of Kentucky.

Current data suggest that more than half of those injured are under the age of 21 years at the time of the injury. The growth in the number of children injured can be expected to add to the existing demands on educational programs, as well as on those programs serving persons with developmental disabilities, like the Supports for Community Living Medicaid Waiver program.

A significant proportion of brain injuries occur as a result of motor vehicle accidents, including motorcycle and ATV mishaps. Many of these injuries may be preventable. Given the alarming increase in the prevalence of brain injury each year, efforts to address the prevention of brain injury by increasing seat belt and helmet use, as well as to improve safe driving and safer highways are justified.

## II. Payment for Services for Individuals with Brain Injury

To assess the impact of a growing population of children and adults with brain injury on the demand for publicly funded programs, it is important to identify the payor sources being accessed to pay for services. Data to answer the following questions has been identified in the Surveillance Registry project report and in the final report of the Acquired Brain Injury Planning Grant Report, completed by the Brain Injury Services Unit in 2000.

### Who paid for hospital care at the time of the brain injury?

Table 6 details the primary payers for hospital based treatment for brain injury for the year 2000, which is most recent year for which data were available (Christian, 2003).

**Table 6. Primary Payers for Traumatic & Acquired Brain Injury Hospital Care as Identified in 2000 Hospital Discharge Data**

| Primary payer | TBI % | ABI % |
|---|---|---|
| Medicare | 22.1 | 37.3 |
| Medicaid | 10.5 | 15.9 |
| Workers Compensation | 3.6 | 0.9 |
| Insurance company | 27.5 | 11.5 |
| Commercial-Indemnity | 14.8 | 7.6 |
| Commercial-Managed Care | 2.5 | 2.8 |
| Commercial-Preferred Provider | 1.9 | 2.7 |
| BlueCross/Blue Shield | 2.4 | 2.9 |
| Commercial-HMO | 1.3 | 3.4 |
| CHAMPUS | 0.5 | 0.5 |
| Other Federal programs | 0.2 | 0.5 |
| Self Pay | 4.2 | 9.0 |
| Other | 8.4 | 5.1 |
| Total | 100 | 100 |

### Who paid for needed services following hospital discharge?

Almost one third (31.6%) of the injured persons used professional services after the injury, according to the prevalence study by Walker, et al., 2004. Data from this study also suggest that between 202,488 and 214,032 Kentuckians with brain injuries need services now or in the future. Table 7 identifies the types of insurance coverage for persons following a brain injury as indicated by respondents to the written survey conducted in 2000 as a part of Planning Grant activities (Brain Injury Services Unit, 2000). It is important to note that a greater proportion of individuals appear to rely on Medicaid and Medicare following the injury than at

the time of the injury. It is hypothesized that this is due to the inability to return to employment or to maintain previous employment following a brain injury, thus resulting in a change in health care coverage.

**Table 7: Insurance coverage of survey respondents (N=636)**

| Type of Insurance | % of Respondents |
|---|---|
| Private | 37% |
| Medicare | 32% |
| Medicaid | 29% |
| Both Medicaid and Medicare | 9% |
| Worker's Compensation | 4% |
| KCHIP | 1% |
| Other | 1% |

**Conclusion:**

Current prevalence estimates indicate that as many as 214,032 children and adults in Kentucky may be experiencing problems related to a brain injury that are severe enough to require professional services and supports. This number can be expected to grow, given the annual occurrence of brain injury in the state. The volume of persons needing assistance from publicly funded programs following a brain injury can be predicted to increase significantly over time.

## III. Needs of People Who Sustain Brain Injuries

Information about the needs of children and adults for services and supports following a brain injury may be found in the Report of the Kentucky Acquired Brain Injury Planning Project (Brain Injury Services Unit, 2000), the prevalence study conducted by Walker, et al., 2004, and the report of the National Centers for Disease Control and Prevention to Congress regarding mild brain injury. This information has been used to answer the questions below.

**How many of the people who sustain brain injuries will need supports and services as a result of their injuries?**

Almost one third of the injured persons used professional services after the injury, according to Walker, et al., 2004. The specific services are shown in Table 8 which includes type of services needed and the percentage those reporting a brain injury indicating a need for assistance.

**Table 8. Use of Professional Services**

| Type of professional services reported as needed | Percent of persons reporting need for services |
|---|---|
| Mental health services | 25.8 |
| Specialized equipment | 27.3 |
| Physical therapy, speech or occupational therapy | 42.2 |
| Vocational training | 13.3 |
| Substance abuse counseling | .8 |
| Personal care assistance | 19.5 |
| Environmental modifications | 16.4 |
| Residential treatment or rehabilitation | 21.1 |
| Other medical services | 41.4 |

In its report to Congress on mild traumatic brain injury in the United States (Centers for Disease Control and Prevention, 2003), the Mild Traumatic Brain Work Group indicated that while not often visible, the consequences of a mild brain injury are often not mild themselves. These consequences include memory impairment, headaches, nausea, fatigue, and emotional problems, which can seriously impair the injured person's ability to function and maintain employment. The report further stated that mild brain injury accounts for at least 75 percent of all traumatic brain injuries in the United States.

**What services and supports do people with brain injuries indicate that they need?**

Ninety percent (90%) of all respondents to the written survey conducted by the Brain Injury Services Unit in 2000 indicated a preference for a future living arrangement. Of those persons who responded to the question, the overwhelming majority indicated a preference to live in their own homes or with their families. This is notable because 98 percent of all respondents reported living alone or with family members and these findings strongly indicate a preference to continue to do so. Walker, et al., 2004 also found a high proportion of persons with brain injuries living at home, with almost 85 percent remaining in their natural homes. This suggests that efforts to develop services for people with brain injuries should focus on supporting individuals and families in their efforts to remain at home.

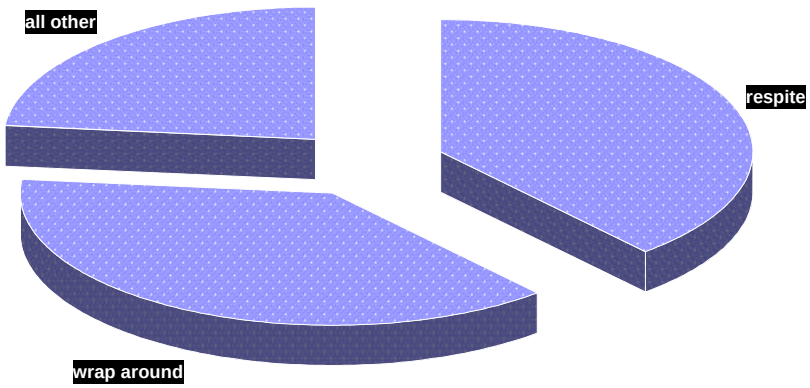
**What do families say they need to help their loved ones remain at home?**

According to focus groups held during the Planning Project, families need the following services and supports to assist them in caring for their loved ones (Brain Injury Services Unit, 2000):

- Respite Care
- Benefits counselors available to assist persons with brain injury and their family members and access to legal and financial counseling
- Life-long case management
- Stress management and wellness services for family members
- Mechanisms to help plan for the future financial security of the injured person after the death of the caregiver
- Alternative Living solutions
- 24 hour crisis support system
- Training and education about brain injury
- Access to psychological services

The Traumatic Brain Injury Trust Fund provides financial assistance to purchase services and supports for which eligible recipients have no other payor source. With the assistance of case managers, recipients direct their own funding. Information about how funds were used by recipients can yield a picture of the services that people with brain injury and their families find helpful in their efforts to remain in the community. Figure 1 illustrates the proportion of funds dedicated to specific types of services and supports by Traumatic Brain Injury Trust Fund recipients, as reported by the administrator of Benefits Management Program. The category of wrap around funds includes, but is not limited to, assistance with rent, mortgage and utilities, transportation & vehicle modifications, medical or dental care, and supervision. It is important to note that the overwhelming majority of funding to assist individuals – 78 percent - is NOT allocated for therapies. Rather, people are seeking relief from the stresses of caregiving and pragmatic assistance in maintaining themselves in their homes.

**Figure 3: Proportion of Services Funded by Traumatic Brain Injury Trust Fund, 2003**




## Conclusion

An estimated one –third of individuals who sustain brain injuries seek treatment for long-term effects of those injuries. While it is estimated that most people with brain injuries sustain a "mild" injury, the consequences of those injuries can be severe. Existing data suggest that those who seek assistance in coping with a long-term disability resulting from a brain injury are seeking help to remain in their own homes. Given the long-term consequences of brain injury, and the preference of persons to remain in their own homes, the creation of an infrastructure to assist them in doing so is paramount.

## IV. Current System Capacity

There are currently two dedicated resources for children and adults with brain injuries in Kentucky: the Acquired Brain Injury Medicaid Waiver Program; and the Traumatic Brain Injury Trust Fund Program.

**Acquired Brain Injury Medicaid Waiver Program** can serve **110 adults** ages 21 to 65 years who meet nursing facility level of care, are financially eligible for Medicaid services, and who show the potential to progress. This intensive rehabilitation program offers fourteen services including case management, day program, supported employment, occupational therapy, speech and language therapy, counseling, behavior programming, companion services, personal care, residential, specialized equipment, environmental modifications, and respite care. **The program is not intended to provide long term care** and its emphasis is on improving or restoring an individual's functioning. This program now has a waiting list of over 50 persons.

**Traumatic Brain Injury Trust Fund Program** is designed to fill the gaps in service delivery that many people with brain injuries experience. To be eligible, an individual must have a brain injury and must have no other payer source for the needed service or supports, including wrap around services. Case management is provided to all recipients. Benefits to recipients are limited to $15,000 annually and $60,000 per lifetime. The cost of case management services is not deducted from the person's annual or lifetime caps. This program can serve approximately 1500 persons annually and now has a waiting list of over 600 children and adults.

**Other Programs.** Children and adults with brain injury may also be eligible for other programs serving persons with disabilities, including:

- Home and Community Based Medicaid Waiver
- Supports for Community Living Medicaid Waiver
- Early and Periodic Screening, Diagnosis, and Treatment funds
- Community Mental Health Services
- Substance Abuse Services
- Vocational Rehabilitation Services
- Educational Services

### Barriers to Accessing Existing Services and Supports

Children and adults with brain injury encounter barriers when attempting to access needed services. Chief among these barriers is a widespread lack of information regarding brain injury and its devastating consequences on an individual and family. Other barriers are detailed below.

**Limited capacity in the community**. The population of Kentuckians with brain injury in need of services is estimated to be between 202,488 and 214,032, and growing (Walker, et al., 2004). Current community based programs dedicated to persons with brain injury in the state can serve approximately 1,600 persons annually – or **less than one percent of those in need of services.**

Similarly, the number of service providers with interest and expertise in offering community based treatment and support to persons with brain injury is extremely limited. There are 27 providers enrolled in the Acquired Brain Injury Medicaid Waiver program statewide. By comparison, there are 112 providers in the Supports for Community Living

program, a number which continues to grow. Of those currently enrolled in the Acquired Brain Injury Medicaid Waiver program, only six providers had a prior history of commitment to, and demonstrated expertise in, serving persons with brain injury at the time of their enrollment, according to the Brain Injury Services Unit, the entity responsible for administering that program. Focus groups and surveys conducted during the Planning Project in 2000 have indicated that when professionals are unaware of the consequences of brain injury and do not have expertise in this area, assessments may be incomplete or inaccurate, leading to ineffective intervention and treatment (Brain Injury Services Unit, 2000).

Arguably, the limited number of community based brain injury providers is a function of the limited number of persons who can be served annually with existing funding. If the needs of the growing population of children and adults with disabilities due to a brain injury are to be met, however, provider capacity within the state must be increased – regardless of funding source.

**Limited inpatient neurobehavioral capacity.** According to the 2002 Report of the Legislative Task Force on Services and Supports for Persons with Traumatic Brain Injury, the capacity to respond to individuals with brain injury who are in crisis due to their behavior is also extremely limited. Pathways Brain Injury Program, located at Christopher East in Louisville, is a specialized neurobehavioral unit which can serve eight (8) individuals in a secure facility. It is licensed as a skilled nursing facility and is funded by both Medicare and Medicaid. If Medicaid is the payor, services must be prior authorized. Caritas Peace Center in Louisville is a psychiatric facility which has established a specialized neurobehavioral inpatient unit serving seventeen (17) adolescents with brain injuries and co-occurring psychiatric disorders. While Medicaid can pay for services to individuals under the age of 21 years and over the age of 65 years in this facility, federal regulations prohibit Medicaid payment for services to adults in freestanding psychiatric hospitals. A total of twenty-five (25) beds are available for persons with brain injury who need neurobehavioral treatment.

By comparison, there is capacity to serve fifty-five (55) adults and seventy-three (73) children with mental illness in crisis stabilization units across the state. State funded psychiatric facilities have the capacity to serve 792 adults and 170 children may be served in psychiatric facilities for children. A total of 713 individuals with mental retardation and developmental disabilities can be served in state operated intermediate care facilities across the state.

Failure to provide treatment for individuals whose brain injury generates risky behavior is generally acknowledged to result in inappropriate hospitalizations and incarceration. Kentucky's safety net for these individuals is inadequate to the numbers of people in need of help.

**Restrictive eligibility requirements.** Eligibility for assistance from non-brain injury programs often depends on the individual with a brain injury demonstrating a second, or co-occurring, disorder such as a severe emotional disorder, a mental health problem, a physical disability or a developmental disability. A brain injury, in and of itself, will not qualify the individual for services.

Medicaid funded waiver programs for which persons with brain injury may be eligible also have restrictive eligibility requirements. Individuals must an institutional level of care to qualify for assistance. It is estimated that 75% of those who sustain a brain injury will suffer a mild brain injury (Centers for Disease Control and Prevention, 2003). However, even a mild brain injury can result in the inability to retain employment, maintain personal relationships, or control one's behavior, resulting in a need for help to cope with the deficits experienced. Few

individuals with a mild brain injury will qualify for assistance from Medicaid funded waiver programs, despite the devastating consequences of their injuries.

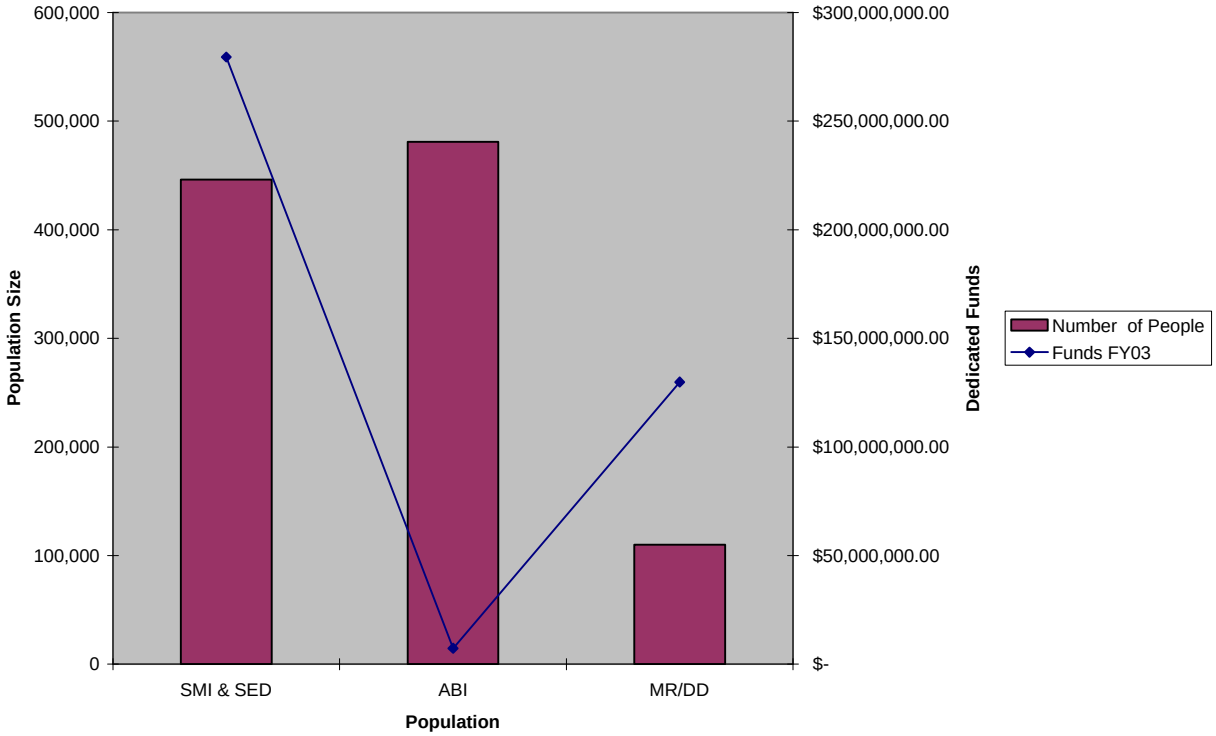
## Funding to Populations of Comparable Size

According to Healthy Kentuckians 2010, an estimated 446, 399 children and adults in the Commonwealth experience some form of mental disorder. According to a prevalence review conducted by Special Olympics, Inc. in 2001, it can be estimated that 110,000 Kentuckians have mental retardation or developmental disabilities. By comparison, an estimated 480,970 persons in the state have sustained a brain injury.

Information about the funding specifically dedicated for community-based services and supports for each of these populations in the fiscal year ending June 30, 2003 was obtained from the Kentucky Department for Mental Health and Mental Retardation Services and the Kentucky Department for Medicaid Services. Funding included approximately $279,537,998 for children and adults with mental illness or severe emotional disorders, $129,833,000 for persons with mental retardation or developmental disabilities, and $7,275,000 for persons with acquired brain injury. These figures include Medicaid and non-Medicaid sources of funding.

Figure 4 illustrates the comparative size of the estimated population of persons with severe mental illness and severe emotional disorders, mental retardation and developmental disabilities, and brain injury, and the amount of funding dedicated to each of these groups in the fiscal year ending June 30, 2003. Clearly, funding for services for children and adults with brain injury is not proportionate to the numbers in need of such services.

**Figure 4: Dedicated Funds per Population, FY03**



## V. Recommendations

Findings to date suggest an immediate need for state attention to the development a comprehensive infrastructure for the staggering number of children and adults with brain injuries in Kentucky. Although brain injury is a problem that has only very recently emerged as a significant health and social problem, it too needs the kind of infrastructure support that has shepherded the development and monitoring of services for persons with other serious health and social problems. The data collected from surveys, surveillance of hospital records, as well as the information obtained from individuals, family members, providers, and policy makers, suggests a need for development of a wide range of services and supports to this ever-growing population. In order to increase the availability and quality of services provided to persons with brain injury in every region of the state several recommendations should be considered:

- Now that data are available on the number of persons with brain injuries in Kentucky, it is time to establish funding for agencies and infrastructural supports on par with those for mental health, mental retardation, and other disability groups

- Long term supports for individuals currently living with their families should be developed for the purpose of assisting them in their efforts to remain in the community, including the establishment of life-long case management services. These supports should be funded outside the Medicaid system to allow access by individuals who will not meet nursing facility level of care. Long term supports should not be interpreted to include the establishment of residential facilities.

- Establish a neurobehavioral inpatient unit for the purpose of providing crisis intervention services to individuals whose brain injury results in serious behavior problems.

- The expertise of providers in non-brain injury service systems should be encouraged by requiring brain injury specific training and coursework in licensure and credentialing standards, as well as in regulations governing the provision of publicly funded services. Additionally, funding should be dedicated for a panel of clinicians and consultants to assist providers in developing their expertise and in addressing the needs of given individuals.

- Given the high costs to society of brain injuries brain injury prevention should become a priority in public safety legislation - including a primary offense seat belt law and a mandatory motorcycle helmet law. Persons under the age of 16 years should be prohibited from operating an all-terrain vehicle.

- Transportation related fines and fees should be reviewed and considered for dedication to brain injury services given the number of persons injured in traffic related mishaps.

Additional copies of this status report may be obtained from:

TBI Trust Fund Board of Directors
C/o Brain Injury Services Unit
100 Fair Oaks Lane, 4WC
Frankfort, Kentucky 40621
502-564-3615

## References


Centers for Diseases Control (2003). *Report to Congress on Mild Traumatic Brain Injury in the United States: Steps to Prevent a Serious Health Problem.* Retrieved December 10, 2003 from: http://apps.nccd.cdc.gov/brfss/page.asp?yr=2001&state=KY&cat=RF#RF.

Christian, W.J. *Traumatic Brain Injury & Spinal Cord Injury Surveillance Project: Fiscal Year 2001 Final Report.* Frankfort, KY: Department for Mental Health and Mental Retardation Services.

Christian, W.J. *Traumatic Brain Injury & Spinal Cord Injury Surveillance Project: Fiscal Year 2002 Final Report.* Frankfort, KY: Department for Mental Health and Mental Retardation Services.

Christian, W.J. *Traumatic Brain Injury & Spinal Cord Injury Surveillance Project: Fiscal Year 2003 Final Report.* Frankfort, KY: Department for Mental Health and Mental Retardation Services.

Christian, W.J., Carroll, M., Meyer, K., Vitaz, T.W., and Franklin, G. (2003). *Motorcycle Helmets and Head Injuries in Kentucky, 1995-2000.* Journal of the Kentucky Medical Association, January 2003.

Kentucky Commission on Services and Supports for Individuals with Mental Illness, Alcohol and Other Drug Abuse Disorders, and Dual Diagnoses. (June 21, 2001). *Template for Change*. Retrieved December 10, 2003, from the Kentucky Department for Mental Health and Mental Retardation Services web site: http://mhmr.chs.ky.gov/MH

Kentucky Department for Public Health. *Healthy Kentuckians 2010.* Retrieved December 10, 2003 from http://www.chs.state.ky.us/publichealth/healthy_ky_2010.

Kentucky Legislative Research Commission (2002). *Report of the task force on Services and Supports for Individuals with Acquired Brain Injuries, Research memorandum No. 496.* Frankfort, KY.

Special Olympics, Inc., (March, 2001). *The Health Status and Needs of Individuals with Mental Retardation*. Authors: Horwitz, S., Kerker, B., Owens, P., and Zigler, E. 1325 G Street, N.W., Suite 500, Washington, D.C., 20005.

Walker, R., Logan, TK, Leukefeld, C., and Stevenson, E. (2004). *Kentucky Traumatic Brain Injury Prevalence Study*. Frankfort, KY: Department for Mental Health and Mental Retardation Services.